ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes
Northside Virtual MM Support Group
May 7, 2022

Business & News:

Thank you **Nancy** for hosting the meeting. 28 members were in attendance. The group welcomed **Dr. Kathryn Maples, Pharm D**. oncology pharmacist from Emory. She is the myeloma drug expert in the pharmacy department and clinical trials. She was excited to meet with our group and discuss myeloma treatments and drug therapies.

Guest Speaker Presentation:

Dr. Maples started her presentation with a few slides as an overview of myeloma. She reviewed the myeloma drug chart by class. *Immunomodulatory drugs (IMID)* include Thalidomide, Revlimid, and Pomalyst. *Proteasome inhibitors (PI)* are Velcade, Kyprolis, and Ninlaro, and the *Monoclonal Antibodies* class (MoAb) drugs are Darzalex, Empliciti, and Sarclisa. *Nancy's Drug Class List by Class file is attached below.* Dr. Maples discussed how these drug classes and several new agents are providing positive results in myeloma treatment. Many novel immune therapies are used in new ways: Blenrep (drug conjugate), Abecma (CAR –T-cell), Carvykti (CAR –T-cell), Selinexor, and Venetoclax for t(11:14) used off-label. Novel agents and combinations in both frontline and relapsed settings improve both depth of Minimal Residual Disease (MRD pg.24-28) and duration of response rates. PFS (Progression Free Survival) and OS (Overall Survival) rates have significantly increased since the early 2000's when Revlimid and Velcade first became available. More classes of drug and immune therapy, along with a four-drug combination the survival rates will continue to improve. The role of MRD testing will be essential in improving PFS and OS myeloma survival rates in the future.

Dr. Maples presented the *General Principles for RRMM Treatment chart* that illustrates the criteria for evaluating patient status at Relapse/Refractory Multiple Myeloma stage and outlines the process to determine next treatment options. For now, there is no set standard for the next steps in treatment plans for myeloma.

General Principles for RRMM Treatment

- Currently no universal standard for optimal therapy sequence in relapsed/refractory disease

Patient	Disease	Treatment	Regimen
▪ Age ▪ Performance status ▪ Lifestyle ▪ Patient preference ▪ Caregiver support ▪ Comorbidities – Renal status – Neuropathy – Cardiac – Diabetes – Cytopenias	▪ Disease burden: ISS – Rate of progression – Marrow burden – CRAB symptoms – Extramedullary disease ▪ Biology – LDH – Cytogenetics: • t(4;14) • del(17p) • t(14;16) • amp(1q) • t(11;14)	▪ Toxicity – Myelosuppression – Infections – Neuropathy – Secondary cancers – Ocular toxicity ▪ Cost ▪ Administration route ▪ Relapsed vs refractory ▪ Depth/duration of response to prior treatment	▪ Triplet* (eg, KRd) is preferred over doublet ▪ Include ≥1 agent from a new or nonrefractory class ▪ Previously used agents may be effective in different combinations ▪ Treat to maximum response ▪ Maintain on ≥1 agent until progression or intolerability

Laubach. Leukemia. 2016;30:1005.; Sanchez. Expert Rev Hematol. 2020;13:943. Moreau P. *Blood*. 2017;130(13):1507-1513.

The future is bright with the approval of new agents and new combinations through clinical trials and published reports at ASH, ASCO and IMF IMWG . The **STOMP** is a phase 1B/2 clinical trial investigating Selinexor in combo with daratumumab (Sel-Dara/dex), pomalidomide (Sel-Pom/dex), and carfilzomib (Sel-Car/dex) for early relapse. Investigations are ongoing with Blenrep combined with Pom and Velcade. Blenrep is approved only as a single agent. Blenrep is an antibody drug conjugate that has a toxic drug in the backpack of a monoclonal antibody targeting BCMA. Venetoclax combinations include Dara and Car. Two of these trials are available at Emory.

CAR T-cell therapy is also moving forward with the approval of two CAR-T treatments – Abecma and Carvykti. There are several more CAR-T trials, including BB21217, and Allo-715, an "off the shelf" allogeneic CAR-T. Clinical trials in bispecific antibodies therapy are a two-arm delivery where one drug arm attaches to the MM cell and the other arm attaches the target drug to T-cells to attack the MM cell along with the "killer drug." Many of these targets include BCMA on the MM cell: CC-93269, Teclistamab, Elranatamab, REGN5458, and Pavurutamab. There are newer Bispecifics using other targets: GPR5D and FcRH5, with many more to come.
Other drugs in development include:

- Immunomodulatory agents: Iberdomide (CC-220), CC-92480, CFT-7455
- Antibody drug conjugates: HDP-101 (BCMA target), STRO-001 (CD74 target), TAK-573 (CD38 target)
- AO-176 (Anti-CD47 MoAb)
- Immune checkpoint pathway targets: Anti-TIGIT, Anti-LAG
- NKTR-255 (IL-15 receptor agonist)

Dr. Maples noted that clinical trials status at Emory changes often and there are more coming.

Group Discussion Questions:

Q – *Who pays for clinical trials? I am on commercial insurance, not Medicare.* **A** – Medicare covers all FDA approved drugs if they are used the way that they were approved. Co-pays can vary. The medical team does not know what is covered until the patient goes through the process and treatment plan paperwork is submitted. Work with your medical team on additional assistance resources. ***Q*** – *Is one medical insurance company better than another?* **A** – There is not one insurance company that covers all treatments better than others. The insurance coverage and copay can vary. Medicare Part D shows products that are covered. Many patients can get coverage through appeals that are handled by the healthcare team. ***Q*** – *Is off-label usage covered? For example, Venetoclax is used differently than approved by the FDA.* **A** – Insurance is slow to follow NCCN (National Cancer Comprehensive Network). Venetoclax is now listed under NCCN. If you are rejected, submit an appeal. It helps when the treatment is in the NCCN guidelines, or the study is published when reported at ASH. Emory integrated trials with Venetoclax are still open for treatment after the first line of therapy, transplant or not. Requires t(11,14) abnormal chromosomes. ***Q*** – *I had a transplant one year ago and I am on maintenance with Car/Pom/dex. When you say that Emory has trials with Pom, what does that mean?* **A** – Emory has clinical trials with pomalidomide in combination with many new drugs, like Selinexor, Blenrep, and maintenance. ***Q*** – *With each new treatment, it has the potential to be combined with so many other drugs. How do the doctors sort that out?* **A** – "Build your own pizza" options can be exciting and challenging. Trials help to answer which are the best combinations. It could be different for every patient, but the trial data helps guide to the best outcomes. ***Q*** – *Many clinical trials are for abnormal chromosome markers for high risk. I have no markers, so how should my team choose treatment?* **A** – High risk patients need a different level of treatment, but standard risk patients are included in trials. For example, every MM cell expresses BCMA and CD-38, so treatments with those targets are in many clinical trials. There are new combinations being tested in a trial where one drug targets CD-38 and the other uses BCMA as a target. There are trials using the new IMIDs that work differently and boost the immune system which is good with a MoAb that uses the immune system to attack the MM cells. Doctors look at all trials and new combinations to determine what is best for each patient. ***Q*** **-** *Sandy W. noted that dex being part of nearly every MM treatment combination. She said that she currently gets 40 mg. dex in her IV infusion and that she had fewer side effects and psychological issues than 12 or 20mg. in pill form. Any reason?* **A** **-** Dr. Maples said that she cannot explain at the drug level since it is the same formula. They usually recommend that patients try taking the dex at different times. ***Q*** – *Are researchers finding more biomarker targets?* **A** – Yes! Del 17p, t(4.14), t(14,16), gain 1q, e(14,20). Researchers are finding more abnormalities, but do not know yet which ones are high risk markers. ***Q*** – *Are there drugs that are available for extramedullary disease?* **A** – We would like to find a treatment that can specifically treat that situation. In each clinical trial, there are sub-groups identified to compare outcomes which includes extra-medullary along with various abnormal chromosomes. Preliminary data from CC-92480, the new IMID, show it working well in extramedullary MM. Also, Selinexor is showing a benefit as well. ***Q*** – *How long should a patient be on Selinexor?* **A** – Depends on the combination. The **STOMP** combinations are using Dara, Car, and Pom with Selinexor and the median time on the treatment is 12 months. There is really early data, and it varies by combination. **Jim M**. said that Selinexor is the new "weight loss drug" and he is working hard to maintain his appetite. It is an effective drug since his M-spike dropped to 0.1 very quickly. ***Q*** – *An ASH report suggested that maintenance should not automatically be used for all patients. How much and how long is it needed?* **A** – Trials are studying MRD-negative to determine if maintenance should be started right away or when to stop maintenance. It is still too early to make changes to the protocol. Emory feels that maintenance is still important. They want to find out who gets maintenance and who can stop.

Barbara said that she is high risk, del-17p, and knows that she needs to stay on maintenance. She is having a good response and hopes to get to all oral treatment to avoid the trips to the clinic. ***Q*** *– Do I need maintenance after a second transplant?* **A** – The team will look at your previous drugs, response, and side effects, to determine which to use again after transplant. ***Q*** *– How long do stem cells last?* **A** – Researchers are not sure. Nancy said that two members of the group received their stem cells from the freezer 14+ years for another transplant and that were successful. **Jim** said his stem cells are 12 years old and they are talking about a second transplant. ***Q*** *-* ***Dirk*** *has talked to his oncology team during his last visit about splitting up the dex dose. Has anyone tried different times?* **A – Lory** said that she is on Elo/Pom/dex, and she splits up the dex. She takes 10 mg the day before treatment and 10 mg the day that she gets treatment. She takes it at night and sleeps fine the first night but does not sleep well the second night. **Sandy W.** said she takes hers at night and that helps. Splitting them up may extend the impact. Dirk responded that he sleeps well but his judgement is terrible on dex days! He must be cautious on what events or decisions he makes on those days. **Dr. Maples** said that the dex crash is usually within 24-36 hours. Splitting the dose up may soften the crash for some. Some people experiment with timing or spread it out over several days. **Jeff** noted that caffeine with dex causes him to sweat and have a higher pulse rate (over 100). The doctor reduced his dex from 40 mg to 20 mg and he has cut back on caffeine on dex days. Dr. Maples said that the pharmacy team screens for drug interactions. Vitamins and supplements are screened since they can cause interactions. There is good data for many vitamins and supplements and for some others not enough information available. For example, an interaction may inhibit the enzymes in the liver that metabolize and break down the dex to leave the body. You might be taking something that causes the dex to last longer. ***Q*** *– What about Turmeric?* **A** – Turmeric interacts with treatment at a high amount. Turmeric is not absorbed well in pill form. Although the amount is low, it may cause drug interactions. *Dr. Maples asked patients to pause Turmeric supplements.* ***Q*** *– What about flax seed powder?* **A** – There may be some drug interactions, but not well known. ***Q*** *– If you relapse on a drug, are all drugs in the class no longer a treatment option?* **A** – The newer generations of drugs within a drug class can overcome resistance. For example, if Revlimid stops working, Pomalyst could work against the MM. That is the only option in that drug class for now, since we are not using thalidomide in the US due to side effects of severe neuropathy. There are new IMIDs currently in clinical trials on the way. ***Q*** *– I had a transplant and in complete remission. I am still on Revlimid maintenance after five years and want to stop.* **A** – Emory doctors are not ready to stop maintenance. They are still learning which patients to stop. In general, everyone is on continuous maintenance, but each patient is different. Talk to your doctor. ***Q*** *– Is it OK to take collagen?* **A** – It should be OK since no interactions have been found. ***Q*** *– I am taking Colestipol (cholesterol med) once per day and having diarrhea problems. What time should I take a second dose?* **A** – Increase to two pills at the same time and see if that helps

Member updates:

Kyle has myeloma for 17 years. He announced that he will start a new job as a nurse in the cardiac critical care unit at Emory. Congratulations to Kyle for his dedication and hard work to his career change and new position at Emory. **Molly and Bob** joined late to the Zoom session after their MMRF 5K fundraiser at the Westside Quarry Park. Molly said that the park was beautiful with perfect weather for a successful fundraising event. Dr. Lonial ran the 5K again this year.

Submitted by Nancy B.

.

****

Meeting Minutes
Southside Virtual MM Support Group
May 28, 2022

Business & News:

Next Meeting: Saturday, June 25, 2022, 10 AM. We welcome the return of one of our favorite speakers, Tara Roy, MS, NP, the Patient Advocacy Liaison. from Takeda. The topic is **Risk Status in Multiple Myeloma**. Tara explores why *risk status* is important to making myeloma treatment decisions and how it is assessed, including contributing factors.

May is Mental Health Awareness Month. As myeloma patients, caregivers, and supporters, we endure an increasing level of stress. Find ways each day to reduce daily stressors. Calming walks outdoors, deep breathing exercises, belly laughs, aromatherapy, etc. are some of the methods used for stress reduction. This year two tragic mass shootings occurred: one at a local grocery store in Buffalo, NY, and another at an elementary school in Uvalde, TX. We remembered those murdered as **Doris** led us in a moment of silence.

Guest Speaker:

Thank you to **Gail** for hosting the meeting. Our guest speaker was **Udana Dozier** from the **Leukemia and Lymphoma Society (LLS).** She provided information on "Light the Night Atlanta" an annual fundraiser for LLS. This year's event will be held in Piedmont Park on Saturday, October 1. The official start time is 5:30 PM. Parking is a challenge, so you are encouraged to carpool and arrive early. Midtown High School (the old Grady High School) has provided parking in the past for a fee There will be music, entertainment, and fireworks after dark. There are usually two fundraising walking distances. Because of COVID, there may not be food available this year due to COVID, but this is not yet confirmed. Bring your family, the grands… your own chairs, food, and maybe a blanket ~ make it a picnic. This event supports all blood cancers – leukemia, lymphoma, and myeloma. There is an LLS fundraising page for the Southside Support Group under Doris' name. This year's goal is $3,000. You are welcome to set up your own page for donations. Updates with further instructions will be sent out prepare our fundraising efforts. Udana will send her PowerPoint slide deck.

Special Focus – Monoclonal Antibodies

We showed a YouTube video (by Healthtree) on monoclonal antibodies. Monoclonal antibodies are proteins that are artificially created that attack specific sites on the myeloma cell to destroy it. The targets of monoclonal antibodies include CD38, SLAMF7, and BCMA. The class of monoclonal antibodies include Dara, Isatuximab, Elotuzumab. What are Monoclonal Antibodies?

Patient Updates:

Dirk asked the group about their experiences with Kyprolis (Carfilzomib), Pomalyst (Pomalidomide), and Dex. Treatment with Daratumumab (Darzalex) is no longer working for him. Several people in the group have been on this same treatment combination. **Gail** has been on Pomalyst as a maintenance therapy for more than 2 years. **Emma** had been on the KPd combination, but it no longer works. Additional lesions were found in her head. Emma and her sisters have requested a consultation with the doctor since this is such an important decision-making time in her therapy. She is considering a second opinion at the Mayo Clinic. **Alma** was on Kyprolis and went into heart failure.

She was then on Dara which stopped working. She is now in a clinical trial, C220 (Iberdomide) in the same 'IMiD' class with Thalidomide, Revlimid (Lenalidomide) and Pomalyst in the immunomodulatory drug class. **M Williams** has been on that combination of meds for 3 years with no problems so far. She gets her heart checked every six months. **Barbara W.** is also on this combination with only headaches as a side effect so far. She sets up clinic appointments on Friday, so that the worst side effects occur on Saturday. **Gloria T.** is only on two medications – Dara and Dex. And is experiencing real problems with side effects.
Doris shared that her numbers are starting to climb. Diagnosed 16 years ago, she initially started on Thalidomide. Her cells were harvested but she declined a SCT. Doris has been on Revlimid for the past three years after a long remission from Thalidomide. A clinical trial is being recommended. Doris does not like taking meds and would rather take a single medication to see if it works. Gail noted that research evidence shows using a three-drug regimen attacks the myeloma more effectively. **Deborah,** a 40-year veteran oncology nurse, offered her support to Doris and others in the group. She suggested being open to treatment recommendations and focusing on the outcome rather than the number of medications. She also suggested that Doris take her daughter to her appointments. **Sandy B**. shared an unfortunate update on her dental issues. She suddenly notices loosening of her teeth starting in 2019, and it was recommended to extract all her teeth to reduce the possibility of infections. Checking with the dentist and a meeting with IMF staff, this may be a result of Revlimid and Dex. The IMF said that others have reported similar complaints. She has been on very low doses of Revlimid with Dex for about 6 years. Sandy has found a dentist whom she trusts, Dr. Bankston, whose brother also has myeloma and is on Revlimid. We appreciate Sandy for sharing such personal information in an effort to help us all.

The **Men's Only Group** met on May 24. Guest Speaker, **Thomas Goode,** Black patient ambassador and Support Group leader from North Carolina shared his experiences. Thomas is an energetic, positive-thinking survivor since 2005. He has high-risk type of myeloma and has had three stem cell transplants – one autologous and two allogenic, with his brother as his donor. Thomas uses daily cardio and weight training to stimulate and maintain his physical and mental fitness.
Men's Only Group reported a high energy session, with everyone participating and getting to know each other. Everyone had such a good time that the meeting went 30 minutes over the designated time – but no one left. Anderson and Ted said they would continue to get this group more organized and defined. The established date and time for the Men Only Group is the fourth Tuesday of each month at 6:00 PM. Although the meetings are scheduled during the dinner hour, it is the best option for the group until further notice. **Nancy** mentioned that the **IMF** wanted to know their thoughts about inviting other men from across the IMF. **Anderson** and **Ted** said they would like to get this group more organized and defined. Gail shared that the Social Worker at Emory asked for a flyer they could share among their myeloma patients and caregivers.

Respectfully submitted, Gail